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Systematic review of involving patients in the planning and development of health care

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Abstract

Objective To examine the effects of involving patients in the planning and development of health care.

Data sources Published and grey literature.

Study selection Systematic search for worldwide reports written in English between January 1966 and October 2000.

Data extraction Qualitative review of papers describing the effects of involving patients in the planning and development of health care.

Results Of 42 papers identified, 31 (74%) were case studies. Papers often described changes to services that were attributed to involving patients, including attempts to make services more accessible and producing information leaflets for patients. Changes in the attitudes of organisations to involving patients and positive responses from patients who took part in initiatives were also reported.

Conclusions Evidence supports the notion that involving patients has contributed to changes in the provision of services across a range of different settings. An evidence base for the effects on use of services, quality of care, satisfaction, or health of patients does not exist.

Introduction

Over the past 20 years, governments throughout western Europe and North America have encouraged patients to contribute to the planning and development of health services. In England and Wales the involvement of patients is central to current efforts to improve the quality of health care.¹ Underlying these changes is the belief that involving patients leads to more accessible and acceptable services and improves the health and quality of life of patients.^{2,3} This view is endorsed by government policy, which states that involving patients leads to “more responsive services and better outcomes of care.”⁴

Several authoritative guides to different ways to involve patients in the planning and development of services have been published.^{3,5,6} Involving patients is becoming less discretionary and more compulsory for the providers of services, but engaging patients is not an easy task, and no consensus on which methods are most effective under different circumstances exists.⁴ We therefore carried out a literature review to examine the

effects of involving patients and the circumstances in which these take place.

Methods

We identified papers for possible inclusion by combining searches of electronic databases, hand searches of reference lists of papers, contact with experts in the field and groups of patients belonging to the national Patients Forum, and a purposive hand search of grey literature held at the King's Fund and Department of Health libraries. Electronic databases searched comprised medical literature (Medline from 1966, Embase from 1988, PsychINFO from 1967), nursing literature (CINHAL from 1982), healthcare management literature (HMIC and HELMIS from 1983), and grey literature (EAGLE from 1980). We used medical subject headings and free text searches related to “user involvement”—combinations of “client,” “consumer,” “patient,” “user” and “empowerment,” “involvement,” “participation,” “representation,” for those related to planning and delivering health services—combinations of “health,” “health care,” “health services,” “service,” “welfare” and “delivery,” “development,” “organisational delivery,” “organisational change,” “organisational development,” “planning,” “provision.” Searches were restricted to papers published in English between January 1966 and October 2000.

Criteria for selection

We included papers that described the involvement of patients, defined as “the active participation in the planning, monitoring, and development of health services of patients, patient representatives, and wider public as potential patients.”⁶ We included all papers that described the effects of involving patients in the planning and development of health care. Excluded papers described patient involvement in other activities such as research, community development, health promotion, self management and self help, and the role of doctors and patients in determining individual treatment choices. We also excluded papers that described the measurement of patient satisfaction or patient preferences without describing how this information was used to help development of the service.

Two researchers (DR and CM) independently examined titles and abstracts of papers to decide if the

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full text articles should be obtained. Where there was disagreement, this was resolved through consultation with a third reviewer (MJC). Full text articles were then examined and additional papers excluded if a more detailed examination showed that papers did not fit the study's aims.

Qualitative analysis

When reading articles for inclusion in the review each reviewer (DR, CM, or MJC) completed an annotation form. This allowed the reviewer to describe the nature of the evidence contained in the paper (quantitative research, qualitative research, review of previous literature, case study, expert opinion), the context of involvement (geographical setting, nature of the service, and patient group), the method used (for example, survey, patient representation at meetings), and finally whether or not outcomes of involvement were reported. Classifying papers in this way allowed us to develop a series of categories represented by keywords that were entered onto a bibliographic database and subsequently used to search for papers illustrating particular themes. An initial examination of findings showed that most papers that presented outcomes of involvement were case reports from workers involved in projects. Our approach to data analysis was therefore restricted to a narrative account of outcomes of involving patients and the nature of the evidence used to support these claims.⁷ Because no system for rating the quality of information in case reports exists, we could not assign quality ratings to the papers we included.

Results

We found 337 studies about involving patients in the planning and development of health care. Of these, we excluded 294 (87%) because they did not describe the effects of involvement.

Accepted studies included 42 papers (12%) that described the effects of 40 initiatives involving patients (table 1). Of these, 31 were case reports, five were the results of surveys, three examined records of meetings, and three described the findings of action research. Four reports clearly described the use of qualitative research methods. We did not find any reports that used comparative or experimental research methods. Papers described a range of different models of involvement applied in a range of settings in hospitals and the community. The different effects of involving patients and the nature of the evidence to support these findings are summarised in table 2. We were unable to identify any reports that investigated the effects of involving patients on the health, quality of life, or satisfaction of those using services.

Effects on users involved

Several papers commented that patients who participated in initiatives welcomed the opportunity to be involved and that their self esteem improved as a result of their contributions.⁸⁻¹⁴ The findings of surveys and interviews with patients are in support.^{15 16} We also identified reports in which patients described dissatisfaction with the process.^{17 18} Several studies commented that staff involved in initiatives found the experience rewarding,^{9 19 20} but others describe difficult relationships between patients and staff.²¹

Changes to services

Among the most frequently reported effects of involving patients was the production of new or improved sources of information for patients.^{8 22-30} Other changes included efforts to make services more accessible through simplifying appointment procedures,^{26 30-32} extending opening times,^{24 29 31} improving transport to treatment units,^{15 23 26} and improving access for people with disabilities.^{8 26}

Several reports describe new services being commissioned as a result of the requests of patients, including advocacy,^{24 27} initiatives aimed at improving opportunities for employment,^{15 24} complementary medicine,²³ crisis services,¹⁶ and fertility treatments.³² Two reports describe how involving patients led to proposals to close hospitals being modified or abandoned.^{33 34}

Other effects of patients being involved

Eight reports state that initiatives had a more general effect on organisational attitudes to involving patients. These included comments that staff attitudes to involving patients became more favourable^{8 16 19 35} and that the culture of organisations changed in a way that made them more open to involving patients.^{27 35} Some projects resulted in further initiatives aimed at strengthening the involvement of patients.^{36 37} Concerns were also expressed by researchers who found evidence that involving patients was used to legitimise decisions that would have been made whether or not patients supported them.^{19 38-40} One report concluded that the decision making process was slower because patients were involved.¹⁸

Overall impact of involvement

Attempts to gauge the overall impact of involving patients have been made by conducting surveys of participants and retrospectively examining records of meetings. A survey of the leaders of public involvement initiatives of Health Systems Agencies in the United States in 1980 asked respondents to judge the effects of involving patients.^{41 42} Of the 154 (76%) who replied, 75% (116) said that involving patients had improved the quality of health services and 46% (71) that it had led to improvements in people's health. Of 63 patient participation groups in primary care settings surveyed in Britain in the mid-1980s, 32 (52%) were able to provide details of at least one change that groups had initiated.³¹

Facilitated meetings between workers in primary care and patients with diabetes in 17 primary care centres in Stockholm in the mid-1980s generated 196 plans for improving patient care. Eighteen months later the extent to which plans had been implemented was evaluated: 70% (137) of plans had been implemented.²⁹ A retrospective examination of records from meetings of five mental health forums in Kent, United Kingdom, identified 57 concerns raised by groups over a two year period.⁴³ Of these, 22 (39%) resulted in a response from providers of services that was judged acceptable.

Discussion

A review of more than 300 papers on involving patients in the planning and development of health care found that few described the effects of this

Table 1 Reports providing details of the effects of involving patients in planning and delivering health care

Study	Nature of evidence	Form of involvement	Nature of service	Location	Reported outcomes
Carlson and Rosenqvist ²⁹	Retrospective review of records	Consultation meetings with 34 patients	Diabetes management in primary care	Sweden	Changes to organisation of care and information for patients
Milewa ⁴³	Retrospective review of records	Five patient forums	Mental health	UK	Unspecified changes to organisation and delivery of services
Nutt ⁵⁰	Retrospective review of records	Patient representation at 12 planning meetings	Primary care	USA	Broad range of suggestions for changes to services
Pilgrim and Waldron ²⁴	Action research	Patient group with 14 members	Mental health	UK	Extension of community mental health team hours; advocate funded; service information for users published
Sheppard ⁹	Action research qualitative methods	Meetings with patients at five general practitioners' practices	Primary care	UK	User involvement appreciated by patients and providers
Taylor ⁴⁰	Action research	Range of consultation projects across all sectors and stakeholders	Learning disability	UK	Implementation of revised patient information; patients' input into substantial overhaul of services
Bowl ¹⁷	Telephone survey of 31 managers; case studies	Patient forums	Mental health	UK	Patient dissatisfaction
Checkoway et al ⁴¹ Checkoway ⁴²	Survey of 154 service providers	Patient representation at meetings	General health	USA	Increased confidence of users who participate; changes to services provided
Hendessi ⁸	Survey of service providers	London based patient groups and forums	Broad range	UK	Changes in policy, quality and methods of service delivery
NHSE ³²	Survey of service providers	Mixed involvement initiatives	Range of settings	UK	Simplified procedures; provision of new services
Richardson and Bray ³¹	Postal survey	63 patient participation groups	Primary care	UK	Reorganisation of waiting rooms; development of new clinics; changes to opening times
Todd et al ¹⁸	Interviews, qualitative analysis	Patient and carer representation on planning boards	Learning disability services	UK	User and carer dissatisfaction
Atkinson and Farshi ⁵¹	Case study	Audit involving interviews with 32 service users	Community paediatric	UK	Changes to dissemination of information
Barnes ¹³	Case studies	Three user groups	Mental health	UK	Improved self esteem
Barnes ⁵²	Case study	User committee	Community care for physically disabled	UK	No changes implemented
Berger et al ¹²	Case study	Consumer committee	HIV clinic	Australia	Patient friendly services and support; improved self esteem of patients
Broderick ³³	Case study	Survey of 140 people by CHC	General health	UK	Reversal of plan to close hospital
Dixon et al ⁵³	Case study	Two patients employed as consumer advocates in assertive outreach team	Mental health	USA	Improved engagement with patients and staff awareness, but problems with boundaries
Elizabeth ¹⁴	Case studies	Three citizens' juries	General health	UK	Increase in participants' self confidence and interest in local democracy
Gummer and Furney ²⁷	Case study	Staff-patient forum: patients represent six groups	Mental health	UK	Improved design of new services; plan for advocacy; improved information, training and recruitment; culture shift; increased user self esteem
Harris ³⁷	Case study	Patient forum	Mental health	UK	Promoted further user involvement
Harrison and Mort ³⁹	Case studies	Health panels run by CHC	General health	UK	Little evidence of changes to services
Heginbotham ³⁴	Case studies	Range of initiatives including campaign by CHCs	Broad range	UK	Reversal of plan to close hospital
Kirk et al ³⁸	Case studies	Range of initiatives including interviews with service users	Primary care	UK	Supported existing plans for expansion of services
Lord et al ¹⁶	Case study with qualitative methods	Stakeholder meetings including service users	Mental health	Canada	Shift in service delivery toward individualised care; broader based ownership and control
Millet ²⁸	Case studies	Survey of 120 patients and three focus groups	Medical outpatients	UK	Development of information and shared care record book
NHS Executive ²⁵	Case studies	Mixed methods (surveys, meetings)	General health	UK	Impact on strategies unclear; some service improvements, better communication with local residents
Pagett ²⁶	Case study	Service users panel	Medical outpatients	UK	Patient information and appointment cards revised; disabled facilities improved
Pecarchik et al ⁵⁴	Case study	Health and welfare council	General health care	USA	Pressure from service users speeded up changes to organisation of blood banks
Poole ²⁰	Case study	User focused monitoring	Neurological disorder	UK	Patients and staff found user involvement rewarding
Sheahan ⁵⁵	Case study	Survey of discharged patients	General hospital care	Australia	Development of information booklet
Silva ¹¹	Case study	Client group to plan respite facility	Mental health	USA	Clients directed service design; became volunteer staff; reduced dependency
Smith ¹⁰	Case study	Ex-client representation at meetings, survey of current clients	Mental health	USA	Promotion of rehabilitation through enhanced self worth, self reliance
Summers and McKeown ^{19†}	Case study	Mixed: focus groups, consultation, interviews, patient survey, and CHC	Maternity services	UK	Strategy reflects call for more linkworkers; better catering; staff interest in user views stimulated
Summers and McKeown ^{19†}	Case study	Mixed: focus groups, user forum, survey of voluntary organisations, and CHC	Mental health	UK	Improved self esteem for users; staff interest in user views stimulated
Tishler ⁵⁶	Case study	Consumer board overseeing service providers	Mental health	USA	Training for staff on patient needs
Williams ³⁰	Case study	Patient and staff interviews; survey	Outpatient services	UK	Waiting times, notes retrieval, patient information, and feedback to patients improved
Wistow and Barnes, ¹⁵ Barnes and Wistow, ³⁵ and Barnes and Wistow ³⁶	Case study with qualitative methods	Survey, citizen advocacy, meetings	Community health and social care	UK	Improved access to services; enhanced self esteem of users who participated; service provider became more open to user involvement
Woods ²³	Case study	Questionnaire survey	Surgical inpatient	UK	Revised admissions and discharge procedures and information; improved ancillary services; complementary medicine; liaison group established
Young ²¹	Case study	Lay board of directors controlling a primary care clinic	Primary care	Canada	Dissatisfaction among service providers

CHC=Community Health Council.

*A form of quality assessment by service users. †Two separate case studies in one report.

process. Those that have done so are generally case studies where project administrators running projects have commented on what the project achieved. Although these reports support the view that involving patients has contributed to changes to services, the effects of involvement on accessibility and acceptability of services or impact on the satisfaction, health, or quality of life of patients has not been examined.

We found some of the most informative material for this review in grey literature. While we made considerable effort to locate grey literature, the methods we used would not have identified all reports on this subject, especially those from outside the United Kingdom. Another potential problem in interpreting the results is that publication bias may favour the publication of reports from initiatives that were judged to be successful.

Several factors may account for our central finding, the limited amount of information about the effects of involving patients. The aims of involving patients have always been broader than just improving the quality of health care. Involving patients has been viewed by many as a democratic or ethical requirement: because patients pay for services they have a right to influence how they are managed.^{44 45} An alternative view is that involving patients is not intended to devolve power to patients but to legitimise the decisions of policy makers and administrators.⁴⁶ It is argued that through consulting with users of health services, support for decisions that would otherwise be unpopular can be obtained.⁴⁷ Such aims imply that establishing mechanisms for involving patients should be seen as an end in itself rather than as a means of improving the quality of services. However, initiatives that fall short of bringing about changes to services are not in keeping with the aims of current policy or patients.

The effects of involving patients are likely to be complex, affecting different aspects of services in different ways. The views of patients are among many factors that influence change in health services, and providers of health care remain the final arbiter of how much weight is attached to patients' views.¹⁴ Separating out change specifically attributable to the participation of patients is a difficult task.⁴⁸ Despite these problems, possible effects, amenable to formal evaluation, of involving patients have been discussed, including extent of use of the service, satisfaction, and quality of life.² Patients' involvement is not without its costs,⁴⁹ and including outcome measures in future evaluations of involving patients could enable comparisons of different approaches and evaluation of the effects of suggestions made by patients.

Table 2 Nature of evidence supporting effects of involvement of patients in planning and delivering health care

Effect	Quantitative research (observational or experimental studies)	Qualitative research	Case studies
Positive effects on patients who participate	×	✓	✓
Negative effects on patients who participate	×	✓	✓
Changes to information given to patients	×	×	✓
Changes to existing services	×	✓	✓
Development of new services	×	✓	✓
Increased use of services	×	×	×
Increased satisfaction among patients	×	×	×
Improved health or quality of life for patients	×	×	×

What is already known on this topic

Involving patients in planning and delivering health services is recommended as a means of improving the quality of services

Methods for engaging with patients have been considered in depth, but the effects of involving patients are less clear

What this study adds

Few studies have explored the effects of involving patients

Involving patients has contributed to changes in service provision, but the effects of these on quality of care have not been reported

Conclusions

Patients have contributed to the planning and development of services across a range of settings, but the effects of this process on the quality and effectiveness of services are unknown. This absence of evidence should not be mistaken for an absence of effect. Healthcare providers may be increasingly required to demonstrate that they involve patients in the planning process, but they will also continue to be accountable for the decisions they make. A better evidence base may be necessary to persuade providers to place greater emphasis on patients' views when making decisions about services.

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